



TESTIMONY BEFORE THE HOUSE COMMITTEE ON WAYS & MEANS

FOR THE HEARING ON THE PRESIDENT'S FISCAL YEAR 2013 BUDGET PROPOSAL WITH
U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES SECRETARY KATHLEEN SEBELIUS

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BY THE

NATIONAL HEALTH LAW PROGRAM

The National Health Law Program (“NHeLP”) submits this testimony to the House Committee on Ways & Means. NHeLP protects and advances the health rights of low income and underserved individuals. The oldest non-profit of its kind, NHeLP advocates, educates and litigates at the federal and state levels. Consistent with this mission, NHeLP works to ensure that all people in the United States—including women—have access to quality health care including preventive health services. The Patient Protection and Affordable Care Act (“the ACA”) similarly recognizes that preventive health services are critical to individual and community health, and that cost is often a barrier to accessing needed preventive services. The ACA also acknowledges the critical role that a woman’s health plays in the health and well-being of her family and her community, as well as women’s disproportionately lower earnings, by explicitly requiring that women’s preventive health services be covered without cost-sharing.

Healthcare coverage decisions should be based on accepted standards of medical care recognized by the various professional medical academies. “Standards of care” are practices that are medically appropriate, and the services that any practitioner under the circumstances should be expected to render. Every person who enters a doctor’s office or hospital expects that the care he or she receives will be based on medical evidence and meet accepted medical guidelines – in other words, that care will comport with medical standards of care. Refusal clauses and denials of care, however, violate these standards. They undermine standards of care by allowing or requiring health care professionals and institutions to abrogate their responsibility to deliver services and information that would otherwise be required by generally accepted practice guidelines. Ultimately, refusal clauses and institutional denials of care conflict with professionally developed and accepted medical standards of care and have adverse health consequences for patients. NHeLP’s publication, *Health Care Refusals: Undermining Quality Care for Women* (Appendix A), is an extensive analysis of medical standards of care for women's health and the impact of refusal clauses and institutional denials of care on health access and quality.¹

¹ Susan Berke Fogel & Tracy A. Weitz, *Health Care Refusals: Undermining Quality Care for Women*, Nat’l Health Law Program (2010),

http://www.healthlaw.org/images/stories/Health_Care_Refusals_Undermining_Quality_Care_for_Women.pdf.

NHeLP strongly supports the Department of Health and Human Services (HHS) requirement that most new health insurance plans cover women's preventive health services, including contraception, without cost-sharing. The decision significantly benefits millions of women who are currently insured or who will obtain health insurance through the ACA—and one that will ensure that most women have access to contraception without expensive co-pays, saving some women up to \$600 per year. The Administration recently adopted a religious employer exemption that would allow certain religious employers to refuse to cover contraception, as they would otherwise be required to do, and also announced that it will develop rules to ensure that women can obtain contraceptive coverage at no additional cost while also allowing non-profit religiously-affiliated employers, such as hospitals or universities, to refuse to provide contraceptive coverage. Despite these accommodations, the drive to deprive women of the right to obtain affordable birth control continues. NHeLP strongly opposes efforts to undermine the health and autonomy of women. Every woman should be able to make her own decisions about whether or when to have children based on her own beliefs and needs. Employers and insurance companies should not be able to impose their ideology to override the health care decisions of individual women.

A. THE REQUIREMENT TO COVER CONTRACEPTIVES AS A COMPONENT OF PREVENTIVE CARE IS EVIDENCE-BASED.

The ACA requires group health plans and health insurance issuers to cover certain preventive services without cost-sharing.² Among other things, the ACA requires new group health plans and health insurance issuers to cover such additional women's health preventive care and screenings as provided for in guidelines supported by HHS.³ By doing so, the ACA recognizes that women have unique reproductive and gender specific health needs, disproportionately lower incomes, and disproportionately higher out-of-pocket health care expenses. HHS commissioned the independent Institute of Medicine of the National Academies ("IOM") to conduct a scientific review and provide recommendations on specific preventive measures that meet women's unique health needs and help keep women healthy. HHS charged the IOM with convening a committee to determine the preventive services necessary to ensure women's health and well-being.⁴

To this end, the IOM convened a committee of 16 eminent researchers and practitioners to serve on the Committee on Preventive Services for Women.⁵ The Committee met five times in six months.⁶ It reviewed existing guidelines, gathered and reviewed evidence and literature, and considered public comments.⁷ In reaching its recommendations the IOM also relied on the input

² Patient Protection and Affordable Care Act ("ACA"), Pub. L. No. 111-148, 124 Stat. 119 (2010), amended by Health Care and Education Reconciliation Act, Pub. L. No. 111-152, 124 Stat. 1029 (2010), § 2713(a), 42 U.S.C. § 300gg-13.

³ ACA § 2713(a)(4), 42 U.S.C. § 300gg-13.

⁴ Inst. of Medicine of the Nat'l Academies, *Clinical Preventive Services for Women: Closing the Gaps* (2011), www.iom.edu/~media/Files/Report%20Files/2011/Clinical-Preventive-Services-for-Women-Closing-the-Gaps/preventiveservicesforwomenreportbrief_updated2.pdf.

⁵ *Id.*

⁶ *Id.*

⁷ *Id.*

of independent physicians, nurses, scientists, and other experts. With respect to women, the IOM identified gaps in the coverage for preventive services not already addressed by the ACA, including services recommended by the United States Preventive Services Task Force, the Bright Futures recommendations for adolescents from the American Academy of Pediatrics, and vaccinations specified by the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices. The IOM recommended that, among other things, women receive coverage for all United States Food and Drug Administration ("FDA")-approved methods of contraception free of cost-sharing because: (1) pregnancy affects a broad population; (2) pregnancy prevention has a large potential impact on health and well-being; and (3) the quality and strength of the evidence is supportive of the recommendation to provide contraceptive coverage free of cost-sharing.⁸ HHS recently adopted the eight recommendations submitted by the IOM, which include the recommendation that women receive coverage for all FDA-approved methods of contraception free of cost-sharing.⁹ Requiring coverage of all eight preventive services recommended by the IOM, including coverage of all-FDA approved methods of contraception, is good medical and economic policy.

B. CONTRACEPTION EFFECTIVELY PREVENTS UNINTENDED PREGNANCIES, AND WOMEN NEED TO BE ABLE TO SELECT THE METHOD THAT IS MOST APPROPRIATE.

Family planning is an essential preventive service for the health of women and families. In 2008, there were sixty-six million women of reproductive age (ages 13-44) in the United States.¹⁰ Over half of these women—thirty-six million—were in need of contraceptive services and supplies because they were sexually active with a male, capable of becoming pregnant, and neither pregnant nor seeking to become pregnant.¹¹ Each year, nearly half of the pregnancies in the United States are unintended—meaning they were either unwanted or mistimed.¹² Forty-two percent of unintended pregnancies end in abortion.¹³ By age 45, more than half of all women in the United States will have experienced an unintended pregnancy, and four in ten will have had an abortion.¹⁴ Unintended pregnancy disproportionately impacts women of color: sixty-seven percent of pregnancies among African American women, fifty-three percent of pregnancies among Latina women, and forty percent of pregnancies among white women are unintended.¹⁵ A

⁸ *Id.*

⁹ U.S. Dep't of Health & Human Servs., Health Res. & Servs. Admin., Women's Preventive Services: Required Health Plan Coverage Guidelines, <http://www.hrsa.gov/womensguidelines>.

¹⁰ Jennifer J. Frost, Stanley K. Henshaw & Adam Sonfield, Guttmacher Inst., *Contraceptive Needs and Services: National and State Data, 2008 Update 3* (2010), <http://www.guttmacher.org/pubs/win/contraceptive-needs-2008.pdf>.

¹¹ *Id.*

¹² Lawrence B. Finer & Stanley K. Henshaw, *Disparities in Rates of Unintended Pregnancy in the United States, 1994 and 2001*, Perspectives on Sexual & Reprod. Health, Vol. 38, No. 2 (2006), <http://www.guttmacher.org/pubs/psrh/full/3809006.pdf>; Guttmacher Inst., *Facts on Induced Abortion in the United States* (Aug. 2011), www.guttmacher.org/pubs/fb_induced_abortion.html.

¹³ Inst. of Medicine of the Nat'l Academies, *supra* note 4.

¹⁴ Guttmacher Inst., *Fact Sheet: Facts on Induced Abortion in the United States* (Aug. 2011), http://www.guttmacher.org/pubs/fb_induced_abortion.html.

¹⁵ Lawrence B. Finer & Mia R. Zolna, *Unintended Pregnancy in the United States: Incidence and Disparities, 2006*, Contraception, Vol. 84, No. 5 (2011).

woman has an eighty-five percent chance of an unintended pregnancy if she uses no method of contraception.¹⁶ More than fifty percent of unintended pregnancies in the United States occur among the sixteen percent of women at risk for unintended pregnancy who are not using any contraceptive method.¹⁷ According to the Guttmacher Institute, in the United States publicly funded family planning services and supplies alone help women avoid approximately 1.5 million unintended pregnancies each year.¹⁸ If these services were not provided in 2008, unintended pregnancy rates would have been 47 percent higher, and the abortion rate would have been 50 percent higher.¹⁹ Increased access to, and use of, contraceptive information and services could reduce the rate of these unwanted pregnancies.

However, as the IOM report recognized, not all contraceptive methods are right for every woman, and access to the full range of pregnancy prevention options allows a woman to choose the most effective method for her lifestyle and health status. Current methods for preventing pregnancy include hormonal contraceptives (such as pills, patches, rings, injectables, implants, and emergency contraception), barrier methods (such as male and female condoms, cervical caps, contraceptive sponges, and diaphragms), intrauterine contraception, and male and female sterilization. As the IOM reported, female sterilization, intrauterine contraception, and contraceptive implants have failure rates of less than one percent.²⁰ Injectable and oral contraceptives have failure rates of seven and nine percent, largely due to misuse.²¹ Failure rates for barrier methods are higher.²²

C. CONTRACEPTIVES ARE WIDELY USED IN THE UNITED STATES.

Most sexually active women in the United States use contraception to prevent pregnancy. Contraceptive use is nearly universal in women who are sexually active with a male partner: more than 99 percent of women 15–44 years of age who have ever had sexual intercourse with a male have used at least one contraceptive method.²³ This is true for nearly all women, of all religious denominations.²⁴ Indeed, the overwhelming majority of sexually active women of all denominations who do not want to become pregnant are using a contraceptive method.²⁵ Approximately 98 percent of sexually active Catholic women have used contraceptive methods

¹⁶ *Id.*

¹⁷ Rachel Benson Gold *et al.*, Guttmacher Inst., *Next Steps for America's Family Planning Program: Leveraging the Potential of Medicaid and Title X in an Evolving Health Care System* (2009), <http://www.guttmacher.org/pubs/NextSteps.pdf/>.

¹⁸ Jennifer J. Frost, Stanley K. Henshaw & Adam Sonfield, Guttmacher Inst., *Contraceptive Needs and Services: National and State Data, 2008 Update 5* (2010), <http://www.guttmacher.org/pubs/win/contraceptive-needs-2008.pdf>.

¹⁹ *Id.*

²⁰ Inst. of Medicine of the Nat'l Academies, *supra* note 4.

²¹ *Id.*

²² *Id.*

²³ Williams D. Mosher & Jo Jones, *Use of Contraception in the United States: 1982–2008*, Nat'l Ctr. for Health Statistics, Vital and Health Statistics, Series 23, No. 29 (2010).

²⁴ Rachel K. Jones & Joerg Dreweke, Guttmacher Inst., *Countering Conventional Wisdom: New Evidence on Religion and Contraceptive Use* (2011), <http://www.guttmacher.org/pubs/Religion-and-Contraceptive-Use.pdf>.

²⁵ *Id.*

banned by the Catholic Church.²⁶ Even among those Catholic women who attend church once a month or more, only two percent rely on natural family planning methods to prevent unintended pregnancies.²⁷ Consistent with the data establishing that there is nearly universal use of birth control, a recent poll by Public Policy Polling (“PPP”) shows that fifty-six percent of voters, and fifty-three percent of Catholic voters, support the decision to require plans to cover birth control with cost-sharing.²⁸ Further, according to the PPP poll, fifty-seven of all voters, and fifty-three percent of Catholic voters, think that women employed by Catholic hospitals and universities have the same rights to contraceptive coverage as other women.²⁹

D. COST PREVENTS WOMEN FROM ACCESSING CONTRACEPTIVE INFORMATION AND SERVICES.

One of the major barriers to consistent contraceptive use for women - who are also disproportionately low-income - is the high out-of-pocket cost that ranges from \$30 to \$50 per month. Women who are poor also have unintended pregnancy rates that are more than five times the rate for women in the highest income level.³⁰ In fact, unintended pregnancy rates are highest among poor and low-income women, women aged 18-24, cohabiting women and minority women.³¹ Low-income women are the least likely to have the resources to obtain reliable methods of family planning, and yet, they are most likely to be impacted negatively by unintended pregnancy.³²

Increased use of longer-acting, reversible contraceptive methods, which have lower failure rates, could further help women reduce unintended pregnancy. These more effective methods of contraception, however, also have the most up-front costs, which put them outside of the reach of many women.³³ In 2008, for example, only 5.5 percent of women using contraception chose the more effective and longer-term methods.³⁴ As the IOM recognized, the “elimination of cost sharing for contraception . . . could greatly increase its use, including use of the more effective and longer-acting methods, especially among poor and low-income women most at risk for unintended pregnancy.”³⁵ In this regard, the California Kaiser Foundation Health Plan’s experience is informative. The California Kaiser Foundation Health Plan eliminated

²⁶ *Id.*

²⁷ *Id.*

²⁸ Pub. Policy Research Inst., *February PRRI Religion & Politics Tracking Poll* (Feb. 2012), <http://publicreligion.org/research/2012/02/january-tracking-poll-2012/>.

²⁹ *Id.*

³⁰ Lawrence B. Finer & Stanley K. Henshaw, *supra* note 12.

³¹ Lawrence B. Finer & Kathryn Kost, *Unintended Pregnancy Rates at the State Level*, Perspectives on Sexual & Reprod. Health Vol. 43, No. 2 (2011).

³² Sheila D. Rustgi, Michelle M. Doty & Sara R. Collins, The Commonwealth Fund, *Women at Risk: Why Many Women are Forgoing Needed Health Care* (2009), http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2009/May/Women%20at%20Risk/PDF_1262_Rustgi_women_at_risk_issue_brief_Final.pdf.

³³ Inst. of Medicine of the Nat’l Academies, *supra* note 4.

³⁴ Jennifer J. Frost & Jacqueline E. Darroch, *Factors Associated with Contraceptive Choice and Inconsistent Method Use*, Perspectives on Sexual & Reprod. Health, Vol. 40, No. 2 (2008).

³⁵ Inst. of Medicine of the Nat’l Academies, *supra* note 4.

copayments for the most effective contraceptive methods in 2002.³⁶ Prior to the change, users paid up to \$300 for 5 years of use; after elimination of the co-payment, use of these methods increased by 137 percent.³⁷

E. PREVAILING MEDICAL STANDARDS OF CARE REQUIRE THAT WOMEN HAVE ACCESS TO CONTRACEPTIVE INFORMATION AND SERVICES.

The government should make *health care coverage decisions* based on scientific evidence and good economic policy, not on the religious and moral beliefs of some institutions. Health care refusals and denials of care, also known as “conscience” clauses, are based on ideological and political justifications that have no basis in scientific evidence, good medical practice, or patient needs. These policies violate the essential principles of modern health care delivery: evidence-based practice, patient centeredness, and prevention. “Standards of care” are practices that are medically necessary and the services that any practitioner under the circumstances should be expected to render. Refusal clauses and denials of care undermine standards of care by allowing or requiring health care professionals and/or institutions to abrogate their responsibility to provide services and information that would otherwise be required by generally accepted practice guidelines. Refusal clauses and denials of care allow employers and insurers companies to “opt-out” of meeting medical standards of care.

Women consider a number of factors in determining whether to become or remain pregnant, including: age, educational goals, economic situation, the presence of a partner and/or other children, medical condition, mental health, and whether they are taking medications that are contraindicated for pregnancy. For example, a number of commonly prescribed pharmaceuticals are known to cause impairments in the developing fetus or to create adverse health conditions if a woman becomes pregnant while taking them. Approximately 11.7 million prescriptions for drugs the FDA has categorized as Pregnancy Classes D (there is evidence of fetal harm, but the potential may be acceptable despite the harm) or X (contraindicated in women who are or may become pregnant) are filled by significant numbers of women of reproductive age each year.³⁸ Pregnancy for women taking these drugs carries risk for maternal health and/or fetal health.³⁹ Women taking these drugs who might be at risk for pregnancy are advised to use a reliable form of contraception to prevent pregnancy.⁴⁰

³⁶ Kelly Cleland et al., *Family Planning as Cost-Saving Preventive Health Service*, New Eng. J. Med, Vol. 37., No. 1 (April 2011), <http://healthpolicyandreform.nejm.org/?p=14266>.

³⁷ *Id.*

³⁸ Eleanor B. Schwarz et al., *Documentation of Contraception and Pregnancy When Prescribing Potentially Teratogenic Medications for Reproductive-Age Women*, Annals of Internal Med., Vol. 147, No. 6 (2007); Eleanor B. Schwarz et. al., *Prescription of Teratogenic Medications in United States Ambulatory Practices*, Am. J. of Med., Vol. 118 (2005).

³⁹ *Id.*; David L. Eisenberg et al., *Providing Contraception for Women Taking Potentially Teratogenic Medications: A Survey of Internal Medicine Physicians' Knowledge, Attitudes and Barriers*, J. Gen. Internal Med., Vol. 25, No. 4 (2010).

⁴⁰ *Id.*

Unintended pregnancy is associated with maternal morbidity and mortality. The World Health Organization recommends that pregnancies should be spaced at least two years apart.⁴¹ Pregnancy spacing allows the woman's body to recover from the pregnancy. Further, if a woman becomes pregnant while breastfeeding, the health of both her baby and fetus may be compromised as her body shares nutrients between them. According to the American College of Obstetricians and Gynecologists, women who become pregnant less than six months after their previous pregnancy are 70 percent more likely to have membranes rupture prematurely, and are at a significantly higher risk of other complications.⁴² Recognizing the importance of family planning, HHS included family planning as a focus area of the Healthy People 2020 health promotion objectives.⁴³ Healthy People 2020 aims to increase the proportion of intended pregnancies and to improve pregnancy spacing. Specific indicators of goal achievement include increasing: (1) intended pregnancies from 51 percent to 61 percent; (2) pregnancy spacing to 18 months; (3) the proportion of women at risk for unintended pregnancy who use contraceptives to 100 percent; and (4) the proportion of teens who use contraceptive methods that both prevent pregnancy and prevent sexually transmitted disease to 73.6 percent.⁴⁴

Millions of women live with chronic conditions such as cardiovascular disease, diabetes, lupus, and epilepsy, which if not properly controlled, can lead to health risks or even death during pregnancy. Denying these women access to contraceptive information and services does not comport with medical standards that recommend pregnancy prevention for these medical conditions.

Refusal clauses increase health disparities by imposing significant burdens on the health and well-being of affected women and their families. These are burdens that fall disproportionately and most harshly on low-income women, severely impacting their health outcomes and their ability to give informed consent for medical care. Low-income women, and low-income women of color already experience severe health disparities in reproductive health, maternal health outcomes, and birth outcomes. Cardiovascular disease, lupus, and diabetes, for example, are chronic diseases that disproportionately impact women of color. The incidence rate for lupus is three times higher for African American women than for Caucasian women.⁴⁵ Similarly, although an estimated 7.8 percent of Americans have diabetes, the prevalence rate (the number of cases in a population at a specific time) is higher for women of color in all age groups, with obesity and family history being significant risk factors for Type II diabetes.⁴⁶ Nearly one out of ten African American women and one in fourteen Latinas of reproductive age experience

⁴¹ Cicley Marston, *Report of a WHO Technical Consultation on Birth Spacing*, World Health Organization, (June 13-15, 2005).

⁴² Am. Coll. of Obstetricians & Gynecologists, *Statement of the Am. Coll. of Obstetricians & Gynecologists to the U.S. Senate, Comm. on Health, Educ., Labor & Pensions, Pub. Health Subcomm. on Safe Motherhood* (April 25, 2002).

⁴³ U.S. Ctrs. for Disease Control & Prevention, *Healthy People 2020 Summary of Objectives: Family Planning*, <http://healthypeople.gov/2020/topicsobjectives2020/pdfs/FamilyPlanning.pdf>.

⁴⁴ *Id.*

⁴⁵ U.S. Dep't of Health & Human Servs., Office on Women's Health, *Lupus: Frequently Asked Questions* (June 13, 2001), <http://www.womenshealth.gov/publications/our-publications/fact-sheet/lupus.pdf>.

⁴⁶ U.S. Dep't of Health & Human Servs., Nat'l Diabetes Information Clearinghouse, *Diabetes Overview*, <http://diabetes.niddk.nih.gov/dm/pubs/overview/#scope>; Ann S. Barnes, *The Epidemic of Obesity and Diabetes*, 38 Tex. Heart Inst. J. 142 (2011).

an unintended pregnancy each year.⁴⁷ Inaccessible and unaffordable contraceptive counseling and services contribute to these disparities.

Heart disease is the number one cause of death for women in the United States.⁴⁸ The American College of Cardiology and the American Heart Association Task Force on Practice Guidelines issued specific recommendations for management of women with valvular heart disease.⁴⁹ They conclude that individualized preconception management should provide the patient with information about contraception as well as maternal and fetal risks of pregnancy.⁵⁰ Some cardiac conditions in which the physiological changes brought about in pregnancy are poorly tolerated include valvular heart lesions such as severe aortic stenosis, aortic regurgitation, mitral stenosis, and mitral regurgitation all with III-IV symptoms, aortic or mitral valve disease, mechanical prosthetic valve requiring anticoagulation and aortic regurgitation in Marfan syndrome.⁵¹

The American College of Obstetricians and Gynecologists and the American Diabetes Association have developed practice guidelines for the preconception care for women with pregestational diabetes. According to the American Diabetes Association, planned pregnancies greatly facilitate diabetes care. Their recommendations for women with diabetes with childbearing potential include: (1) use of effective contraception at all times unless the patient is in good metabolic control and actively trying to conceive; (2) counseling about the risk of fetal impairment associated with unplanned pregnancies and poor metabolic control; and (3) maintain blood glucose levels as close to normal as possible for at least two to three months prior to conception.⁵² The American College of Obstetricians and Gynecologists further recommends that “[a]dequate maternal glucose control should be maintained near physiological levels before conception and throughout pregnancy to decrease the likelihood of spontaneous abortion, fetal malformation, fetal macrosomia [excessive birthweight], intrauterine fetal death, and neonatal morbidity.”⁵³

Similarly, contraception plays a critical role in preparing a woman with lupus for pregnancy. Lupus is an auto-immune disorder of unknown etiology which can affect multiple parts of the body such as the skin, joints, blood, and kidneys with multiple end-organ involvement. Often labeled a “woman’s disease,” nine out of ten people with lupus are women.⁵⁴ Women with lupus who become pregnant face particularly increased risks. A large review of United States hospital data found the risk of maternal death for women with lupus is twenty

⁴⁷ Susan A. Cohen, *Abortion and Women of Color: The Bigger Picture*, 11 Guttmacher Policy Review 3 (Summer 2008), <http://www.guttmacher.org/pubs/gpr/11/3/gpr110302.html>.

⁴⁸ Lori Mosca, et al., *Tracking Women’s Awareness of Heart Disease: An American Heart Association National Study*, 109 J. Am. Heart Ass’n 573 (Feb. 4, 2004).

⁴⁹ Robert O. Bonow et al., *Guidelines for the Management of Patients with Valvular Heart Disease*, Am. Coll. of Cardiology/Am. Heart Ass’n Task Force on Practice Guidelines (Comm. on Mgmt. of Patients with Valvular Heart Disease), 98 J. Am. Coll. of Cardiology 1949-1984 (Nov. 1998).

⁵⁰ *Id.*

⁵¹ *Id.*

⁵² Am. Diabetes Ass’n, *Standards of medical care in diabetes-2006*, 29 Diabetes Care S4 (2006).

⁵³ Am. Coll. of Obstetricians & Gynecologists, *ACOG Practice Bulletin No. 60: Pregestational diabetes mellitus*, 115 Obstetrics & Gynecology 675 (2005).

⁵⁴ U.S. Dep’t of Health & Human Svcs., Office on Women’s Health, *supra* note 46.

times the risk of non-lupus pregnant women.⁵⁵ These women were three to seven times more likely to suffer from thrombosis, thrombocytopenia, infection, renal failure, hypertension, and preeclampsia.⁵⁶ Women who suffer from moderate or severe organ involvement due to lupus are at significantly higher risk for developing complications during pregnancy, and the guidelines discussed above regarding chronic disease apply to women with those co-morbidities.⁵⁷ This should be taken into consideration in the decision to become pregnant or to carry a pregnancy to term.⁵⁸

Historically, women with lupus were discouraged by the medical community from bearing children. This is no longer always true, however, pregnancy for women with lupus is always considered high risk, and should be undertaken when, if at all possible, the disease is under control. The National Institute of Arthritis and Musculoskeletal and Skin Diseases (“NIAMS”) recommends that a woman should have no signs or symptoms of lupus before she becomes pregnant.⁵⁹ In addition, NIAMS directs women as follows: “Do not stop using your method of birth control until you have discussed the possibility of pregnancy with your doctor and he or she has determined that you are healthy enough to become pregnant.”⁶⁰

F. DENYING WOMEN ACCESS TO CONTRACEPTIVE INFORMATION AND SERVICES UNDERMINES QUALITY OF CARE FOR WOMEN.

Ideological restrictions occur at various levels, including the institutional and health system level and the political level. Refusal clauses are statutory or regulatory “opt out” provisions that impede patient access to necessary and desired health care services and information. At the institutional level, the restrictions that have the greatest impact on access to care are those imposed by institutions controlled by religious entities. In particular, the Catholic health system has the broadest religion-based health care restrictions. The U.S. Conference of Catholic Bishops has issued *The Ethical and Religious Directives for Catholic Health Care Services* for all Catholic medical institutions. The Directives specify a range of services that are prohibited, including contraception. Refusal clauses at the institutional level undermine medical standards of care by allowing health care systems and facilities to prohibit even willing providers from delivering medically needed care, even in emergencies. At the political level, legislation enacting refusal clauses impose restrictions unrelated to health and safety on women’s ability to access reproductive health care services. These restrictions are driven by political ideology, electoral politics, and other political considerations that have nothing to do with evidence-based medicine.

Broad refusal clauses fail to account for (or even consider) the significant burdens that denials of care have on patients. Existing law already protects health care providers and religious

⁵⁵ Megan E. B. Clowse, et al., *A national study of the complications of lupus in pregnancy*, 199 Am. J. Obstet. & Gynecol. 127e. 1, e.3 (Aug. 2008).

⁵⁶ *Id.* at 127e.3-e.4.

⁵⁷ *Id.*

⁵⁸ Nat’l Inst. of Arthritis & Musculoskeletal & Skin Diseases, *Lupus: A Patient Care Guide for Nurses and Other Health Professionals* 27-62, Patient Information Sheet 4-5 (3d ed. Sept. 2006).

⁵⁹ *Id.* at 45-46, Patient Information Sheet No. 11.

⁶⁰ *Id.* at Patient Information Sheet No. 4.

employers who object to providing certain services based on their religious or moral beliefs. The new HHS contraceptive coverage requirement exempts houses of worship and other religious non-profits that primarily employ and serve people of their faith. Over 330,000 houses of worship will likely fall under HHS' exemption. The requirement that most new health plans fully cover contraception without cost-sharing helps ensure that an individual woman can make her own decision about whether to use birth control. A woman who opposes contraception need not use it. The criticism of the preventive services rule distorts these facts. No one will be compelled to use birth control (of course contraceptive use is nearly universal in women who are sexually active with a male partner, irrespective of religious affiliation). No one will be forced to condone contraceptive use. The rule concerns *contraceptive* coverage only, not abortion. Twenty-eight states already require employers to provide contraceptive coverage; the ACA ensures that women across the country will have the same benefits.

A more expansive refusal clause is therefore not only unnecessary, but would also dangerously threaten women's health and well-being—subjugating a woman's access to health care to the ideological desires of her employer or insurer. Recently proposed refusal clauses, such as S. 2043, S.2092, and S. Amendment 1520 to S. 1813, would expand what an employer or insurance company—religiously affiliated or not—can refuse to cover. S.B. 2043, for example, would permit *any* person, even the owner of a grocery store or car repair shop, to deny his employee coverage for contraception or sterilization services. S.B. 2092 seeks to deny women even access to *information* about birth control and sterilization. S. Amendment 1520 is even broader and allows any employer or insurer to refuse to provide coverage for virtually *any* service otherwise required by the ACA. Not only do these proposals discriminate against women, they undermine the whole point of health insurance, which is to pool and minimize risk. An insurance program that fails to cover services that meet standards of medical care fails at its essential task. It is also inadequate and unsafe.

These proposals are not just bad policy; they also contravene § 1557 of the ACA and Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e *et seq.* Section 1557(b) of the ACA provides that, “Nothing in this title (or an amendment made by this title) shall be construed to invalidate or limit the rights, remedies, procedures, or legal standards available to individuals aggrieved under . . . Title VII of the Civil Rights Act of 1964 (42 U.S.C. § 2000e *et seq.*).” In 2000, the Equal Employment Opportunity Commission made clear that an employer's failure to provide insurance coverage for prescription contraceptives, in an otherwise comprehensive prescription drug plan, constitutes unlawful discrimination under Title VII.⁶¹ Longstanding and settled law recognizes the right of women to have contraception covered in the same way that other drugs are covered by health insurance.

In sum, expansive refusal clauses are inconsistent with medical evidence and the right of all people to access health care that meets modern standards of appropriate medical care. Most women are covered by health insurance offered by their employer.⁶² While most American

⁶¹ U.S. Equal Emp't Opportunity Comm'n, Decision on Coverage of Contraception (Dec. 14, 2000), <http://www.eeoc.gov/policy/docs/decision-contraception.htm>.

⁶² Usha Ranji & Alina Salganicoff, The Henry J. Kaiser Family Foundation, *Women's Health Care Chartbook: Key Findings from the Kaiser Women's Health Survey 10* (2011), <http://www.kff.org/womenshealth/upload/8164.pdf>.

women of reproductive age have some form of private insurance, the extent to which they have contraceptive coverage can differ dramatically depending on their type of insurance.⁶³ The ACA recognizes the importance of preventive services to the health and well-being of individuals, their families and their communities. Preventive services are required to be covered without cost-sharing in order to ensure that all foreseeable barriers to access to preventive services are removed. Allowing employers or insurers to erect new barriers in the form of refusal clauses vastly undermines the promise of the ACA to improve the health of the nation. Every woman should be able to make her own decisions about whether or when to prevent pregnancy based on her own beliefs, not the beliefs of her employer or insurer.

G. CONCLUSION

Refusal clauses and denials of care should be evaluated using the same measurements used to evaluate quality generally, with the goal of providing care that is evidence-based, patient-centered, and preventative. All women should have access to the health care services they need based on medical evidence, their personal health needs, and their own beliefs. Low-income women and low-income women of color are disproportionately burdened by refusal clauses, and existing health disparities are exacerbated. Employers, insurers, and hospital corporations should not be allowed to impose their ideology on women.

For more information or questions, please contact Susan Berke Fogel, Director of Reproductive Health, at fogel@healthlaw.org or (818) 621-7358.

Thank you.

⁶³ The Henry J. Kaiser Family Found., *Key Findings from the Kaiser Women's Health Survey* (July 2005), <http://www.kff.org/womenshealth/upload/women-and-health-care-a-national-profile-key-findings-from-the-kaiser-women-s-health-survey.pdf>.

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